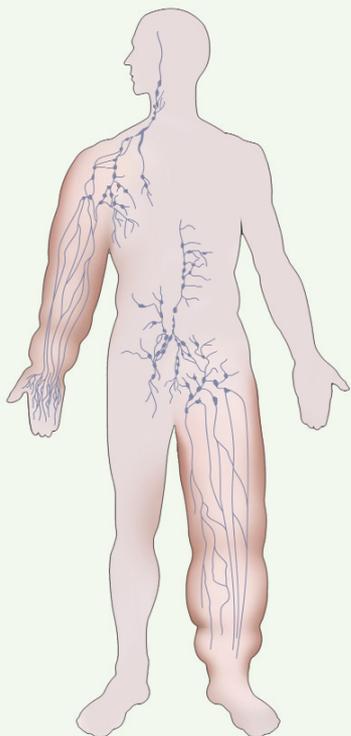


Advice for patients at risk of developing lymphoedema





Conditions related to increased risk of developing lymphoedema:

High risk referral criteria <i>Do you have any of the following?</i>	Additional criteria for increased risk <i>Do you have 2 or more of the following?</i>
Recurrent skin infections (cellulitis)	Obesity
Family history of lymphoedema (mostly limb swelling) - genetic/ inherited lymphatic anomalies	Recurrent ulceration e.g. leg ulcers (damaged lymphatic circulation as a result of vascular disease)
Surgical removal of lymph glands (nodes) or radiotherapy treatment to this area e.g. armpit, groin or neck	Reduced mobility
	DVTs (deep venous thrombosis)
	Coronary artery by-pass graft

This booklet contains important information about lymphoedema. If you have any of the high risk criteria from the table opposite, and/or two or more of the additional criteria, you may be at risk of developing lymphoedema and the following advice will help you:

- to understand the condition
- to reduce your risk of developing lymphoedema
- to recognise the early signs of lymphoedema.

More information about lymphoedema, including details of your local lymphoedema service and how to access it, can be found online via the Lymphoedema Network Northern Ireland website at www.lnni.org

What is lymphoedema?

The lymphatic system is a network of vessels that carry a fluid known as lymph (containing water, electrolytes, proteins and other substances) from the body's tissues. Lymphoedema is the swelling that occurs as a result of a blocked or damaged lymphatic system.

Lymphoedema usually develops in the legs or arms (refer to pages 4 and 5), but can occasionally also develop in the head and neck area, breast and trunk, and genital regions. Some people may have only swelling in one leg or arm, but others may develop swelling in several different parts of the body.

This swelling will cause physical changes, but may also cause psychological stress due to the change in shape, problems with fitting clothes or shoes, and potential reduced mobility. If you feel that you may need access to counselling, please discuss this with your Health Care Professional.

Lymphoedema is a chronic condition and will need to be managed throughout life with the use of a support garment(s) and regular reviews with a lymphoedema specialist.

There are two types of lymphoedema:

1. Primary lymphoedema

This is usually determined from birth due to the underdevelopment of the lymphatic system or absence of lymphatic tissues. It can be present at birth or develop at any stage in life but particularly in adolescents or in mid-thirties. It is a life-long condition that, with help, can be controlled.

2. Secondary lymphoedema

Secondary lymphoedema is caused by trauma or damage to the lymphatic system. This life long risk of developing lymphoedema could be as a result of surgery or radiotherapy to treat cancer. It can also occur as a result of infection, severe injury, burns or any other trauma which may affect the lymphatic system. Examples include:

- Skin infections (cellulitis)
- DVT
- Chronic vascular condition such as leg ulcers

With proper education and care, the swelling can be reduced and lymphoedema can be kept well under control.



Advice for patients 'at risk' of developing lymphoedema

While there is no strong scientific research into how lymphoedema starts, it is believed that you can reduce the risk of lymphoedema by incorporating simple precautionary measures into your lifestyle – looking after your skin, a healthy diet and following a simple exercise programme can help.

How does lymphoedema affect the body?

- What are the signs / symptoms to look out for?

Early signs of lymphoedema may be slight and not noticeable all the time. The swelling may not be as much in the morning, but may become larger in the affected area or limb as the day goes on. If left untreated the swelling may become more permanent and may not go down overnight. The swollen area may begin to feel hard and solid. This is because protein, as well as fluid, has built up in the tissues. Patients may experience symptoms of heaviness, aching or stiffness in the affected area or limb. These symptoms may be felt before the swelling is obvious. It may also be difficult to get clothes, shoes and jewellery to fit.

It is important to start treatment as soon as possible as simple measures may help to reduce swelling in the early stages.



What should you do to reduce the risk of developing lymphoedema?

1. General Recommendations:

- It is very important to keep your weight within normal limits as excess weight can increase strain on the lymphatic system. Following a normal, healthy diet is recommended; reducing protein in the diet will not prevent lymphoedema
- Try to mobilise normally as using your muscles will help to improve lymphatic circulation
- Avoid prolonged periods of standing in one position
- Short periods of daily leg elevation (on a sofa or bed) are recommended. It is not good to always be standing or sitting with the legs down i.e. in a chair

2. Skin care

Skin care is essential in the prevention and management of lymphoedema in order to maintain good skin quality and reduce the risk of infection. Part of the lymphatic system is a fine network of vessels running just below the skin. These vessels help to remove any extra fluid and waste substances from the body's tissues. It is therefore essential to look after the skin to prevent it becoming dry, cracked or broken.

Damaged skin can lead to an infection called **cellulitis** which can increase the risk of developing lymphoedema. Contact your doctor immediately if you notice that your skin has become red, hot and tender, as you may have an infection. This may be preceded by flu-like symptoms.

Cellulitis must be treated quickly with antibiotics prescribed by your doctor.

The CREST Guidelines for the diagnosis, assessment and management of lymphoedema provide details of the recommended cellulitis drug management (Appendix 7). This can be accessed via the LNNI website.

The skin on the feet, especially around and under the toes, can suffer from athlete's foot. This can again lead to open sores and an increased risk of infection. Athlete's foot should be treated with anti-fungal creams completing the prescribed course.

a. Look after your skin:

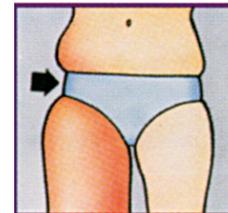
- Cleanse and moisturise your skin daily using unscented soap and cream using gentle strokes
- Protect yourself against excessive heat, which can increase swelling, by avoiding hot baths/showers, saunas and extreme temperatures
- Use nail clippers or emery boards rather than scissors, or access a podiatrist if necessary
- Use electric razors instead of normal razors or hair removal creams (facial hair may be removed by any method that suits)

b. Aim to prevent infection:

- Try to avoid cuts, scratches, burns, insect bites and use antiseptic and antifungal creams when necessary. Monitor any cut no matter how small, even a rag nail
- Try to avoid walking around barefoot as you may damage the skin on your foot



- c. Avoid tight, restrictive clothing*, e.g. tight elastic band on socks, tight waistbands, tight bras or tight wrist watches. Wear comfortable and well fitted shoes.



- 3. Gentle rhythmic exercises** will help to pump the muscles and remove the build up of lymph in the body. It is important to keep as active as possible; swimming, walking and cycling are excellent ways to use large muscles and help to prevent lymphoedema.

Exercise is also important for healthy weight management which will also help to reduce the risk of lymphoedema.

4. Holidays and travel:

- Flying with long periods of inactivity can affect circulation and lymph movement; it may even trigger lymphoedema in people at risk of developing it
- Flight socks should fit correctly, be comfortable and not leave pressure marks on your legs. Poorly fitted flight socks could cause more problems.
- Stretch and move around as much as possible when travelling
- Skincare is very important on holidays; avoid sunburn and insect bites by using sun cream/insect repellent and avoiding excessive sun at the hottest times of the day
- Prevent dehydration by frequently drinking water

Complementary and alternative therapies

The term 'complementary and alternative therapy' covers a wide range of interventions. Those at risk of developing lymphoedema should inform their therapist prior to any treatment, and:

- Avoid very warm and humid environments such as saunas or steam baths
- Avoid very heavy massage e.g. sports, Thai and Rolfing (all massage must be very light)
- Avoid acupuncture to limbs where lymph nodes have been removed or to any limb(s) already identified as being particularly at risk of lymphoedema
- Avoid topical applications which may cause skin irritation e.g. sports/muscle rubs, skin exfoliant scrubs
- Ask your therapist to use only gentle touch techniques.

Check that your therapist is a current member of a recognised professional body for their therapy.

What should you do if you notice swelling?

If you notice swelling, and even if it comes and goes, you should tell your GP or current health care provider, who if necessary will refer you to a specialist lymphoedema therapist.

Early treatment is always recommended when the swelling is soft and easily managed.

What treatment can I get if I begin to develop lymphoedema?

Your doctor will refer you to a trained lymphoedema specialist for assessment and treatment. The therapist may suggest a programme of complex decongestive therapy (CDT) which consists of gentle massage (manual lymphatic drainage, MLD), multi-layer bandaging, skin care and exercises. Skills will be taught to help you to manage the long term condition yourself.

The treatment aims to restore limb size and function, reduce swelling and prevent, or reduce, further episodes of skin infection (cellulitis).

More information about lymphoedema, including details of your local lymphoedema service and how to access it, can be found online via the Lymphoedema Network Northern Ireland website at: www.lnni.org

Useful contacts

Lymphoedema Network Northern Ireland (LNNI)

Email: info@lnni.org

Web: www.lnni.org

Northern Ireland Lymphoedema Support Group (NILSG)

PO Box 851

BT9 6WY

Tel.: 028 9066 7570

Email: info@nilsg.co.uk

Web: www.nilsg.co.uk

The Lymphoedema Support Network (LSN)

St Luke's Crypt

Sydney Street

London

SW3 6NH

Tel.: 020 7351 0990

Email: adminlsn@lymphoedema.freemove.co.uk

Web: www.lymphoedema.org/lsn

The Citizens Advice Bureau

can provide an on-line advice guide to provide information on financial support if required

(www.adviceguide.org.uk/nireland.htm).

